

Health Disparities Issues in Cancer Survivorship: Maryland's Approach to Survivorship Research, Policy and Outreach

Claudia R. Baquet, MD, MPH

Professor Medicine

Associate Dean Policy and Planning

University of Maryland School of Medicine

Director UM Comprehensive Center for Health Disparities Research, Outreach
and Training (NCMHD Export Center P60 MD000532)

PI Maryland Regional Community Network Program (UOI CA114650)

Presentation Overview

- Cancer disparities
- Health disparity issues in cancer survivorship
- Overview of research, outreach and education in cancer survivorship in Maryland's health disparity programs
 - University of Maryland Statewide Health Network (MD Cigarette Restitution Fund Program)
 - UM Export Center (NCMHD/NIH P60 MD000532)
 - U56 MSI-Cancer Center Partnership Planning Grant for Cancer Research, Outreach and Training (NCI U56 CA 96302)
 - Maryland Regional Community Network Program (NCI UOI CA114650)
- Identification of key areas for future research

Cancer Disparities Overview

- Documented for decades
- Observed in rates, contributing factors, and outcomes:
 - Incidence and Mortality
 - Survival: lower survival even when adjusted by stage
 - Stage distribution: more advanced
 - Prognostic factors
 - Risk factors
- Cancer treatment and access to quality care
- Access to pain management and palliative care

Disparities in Clinical Cancer Research Participation

- Representation of African Americans, underserved and the poor in clinical trials is lower than for the general population.
- Low participation in trials may contribute to poorer cancer survival rates.
- Barriers to participate in trials include, patient- and health care professional-centered, research institution, and historical bias
- NIH mandate and national initiatives to increase minority accrual to trials.

Cancer Disparities in Maryland

- Cancer disparities exist in Maryland's minority and rural underserved populations.
 - Highest age-adjusted incidence rates: Blacks for all cancer sites except female breast (all ages)
 - Stage at diagnosis:
 - Whites have a higher localized disease compared to Blacks;
 - Blacks more likely to be diagnosed at regional and distant stages of disease
- Maryland ranks 11th nationally in cancer mortality
 - Age-adjusted mortality rates for Black males are substantially higher than whites in Maryland as well as higher than NCI SEER mortality for black males.
 - Age-adjusted mortality rates for all sites are higher in Baltimore City, the Baltimore Metro Region, rural Eastern Shore and rural Southern Maryland regions than in the state as a whole.
- Rural communities have access, transportation and insurance barriers to quality care

Sources:

Maryland Department of Health and Mental Hygiene. Maryland Cancer Registry: Maryland Department of Health and Mental Hygiene, Family Health Administration, Center for Cancer Surveillance and Control, <http://www.fha.state.md.us/cancer/registry/>.

Neloms S, Ouellet-Hellstrom R, Colvin R, Weeks-Coulthurst P, Matanoski G, Yates K, et al., Cancer in Maryland--1999 Incidence and Mortality Annual Report. Maryland Department of Health and Mental Hygiene, Maryland Cancer Registry, 2001.

Factors Contributing to Cancer Survival Disparities

- Race/ethnicity, socioeconomic status and poverty, cultural attributes, and comorbidities
- Health care determinants (access to care, type of health insurance, quality of care, bias)
- Treatment disparities - Cancer care NOT based on clinical factors and bias in care delivery
- Post-treatment access to and compliance with care
- Biologic and genetic determinants
- Cultural competence
- Low participation and retention rates in clinical trials

The background is a solid blue gradient. A thin, light blue curved line starts from the left edge and arcs across the upper half of the slide. A larger, semi-transparent blue shape, resembling a spotlight beam, originates from the bottom right and points towards the center of the text.

Maryland Community Based Partnerships and Approaches for Addressing Survivorship and Cancer Health Disparities

University of Maryland School of Medicine (UMSOM) Models To Eliminate Cancer and Other Health Disparities

- University of Maryland Statewide Health Network (CRF)
- Comprehensive Health Disparities Research, Training and Outreach Center (P60 Export Center: NCHMD/NIH MD000532)
- Maryland Special Populations Cancer Research Network and Maryland Regional Community Network Program (NCI 5UO1CA-086249/UO1CA114650)
- UMES-UMB Comprehensive Cancer Research Planning Grant (NCI U56 CA096303)
- Mini Medical Schools

Key Elements of UM's Comprehensive Approach to Addressing Health Disparities

- Infrastructure and community capacity in key regions of the state
- Community Partnerships
 - Principles: MUTUAL BENEFIT and RESPECT
- Multi-racial, multi-ethnic and geographic focus
- Rigorous research and translation
- Science-guided policy and policy research
- Leveraging resources for sustainability

Disparity Initiatives in Maryland

- Through these and other programs, the University of Maryland addresses existing cancer disparities in a number of ways, including:
 - Research programs
 - laboratory
 - clinical
 - epidemiologic
 - population sciences, using community-based participatory research
 - Community-based initiatives designed to:
 - Increase health and research literacy and general knowledge about health care and encourage increased empowerment about one's health
 - Increase knowledge, attitudes and practices toward cancer and available screening/diagnostic tests
 - Provide specific education and information to patients and health providers about clinical trials
 - Patient navigation

University of Maryland Statewide Health Network (UMSHN)

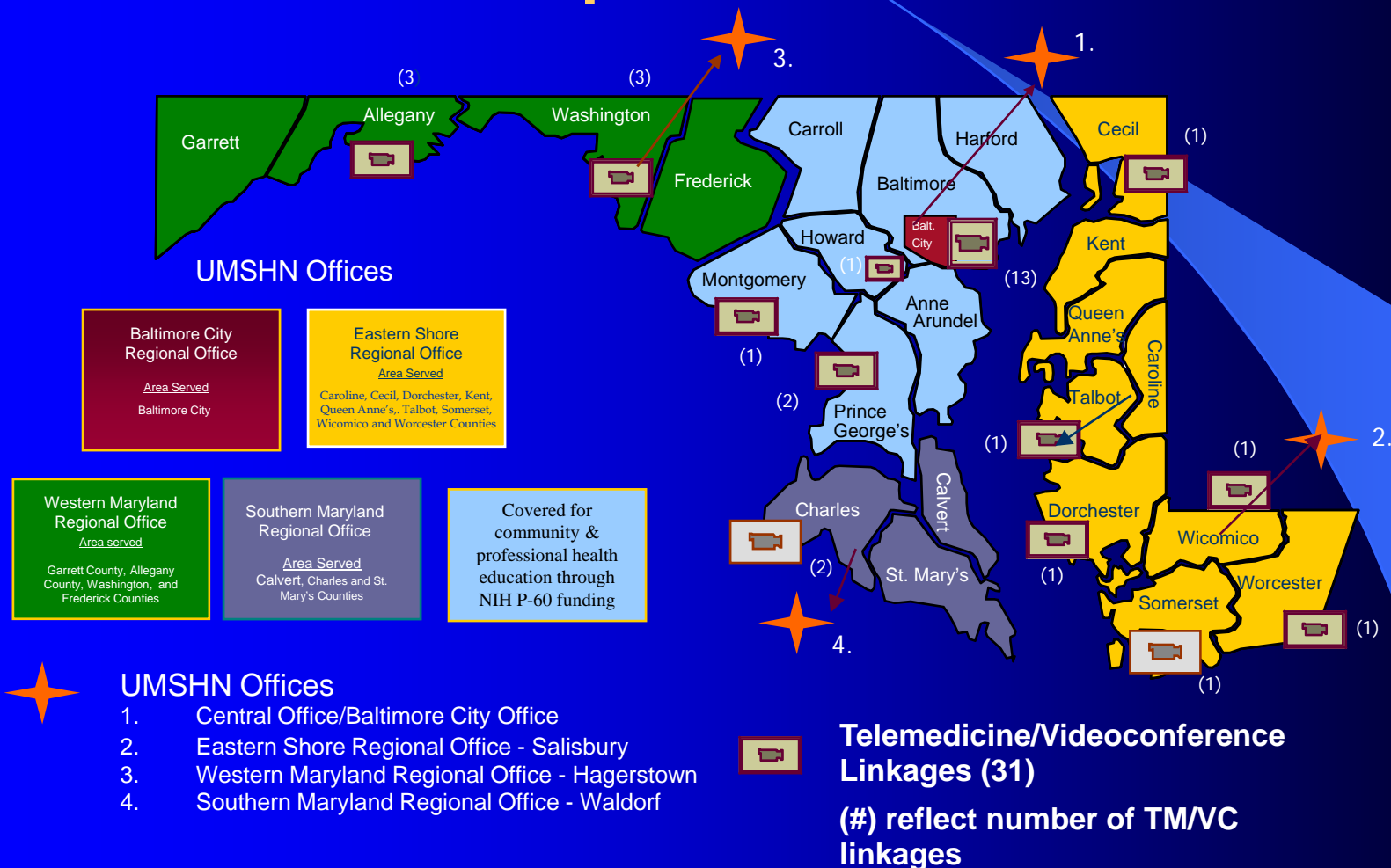
University of Maryland Statewide Health Network (UMSHN): 2000-present

- Mission: To reduce morbidity and death resulting from cancer and tobacco-related diseases and to reduce the disparity in cancer deaths attributable to racial/ethnic, cultural, geographic, or socioeconomic barriers.
- Supports a wide variety of prevention and control activities related to cancer and tobacco-related diseases, including:
 - Activities aimed at increasing participation of diverse populations in clinical trials
 - Development of “Best Practices Models”
 - Coordination among local hospitals, local health departments, community clinics, physicians, and other health care providers
 - Increased access to clinical trials in community settings

Accomplishments

- Community Infrastructure Development and Mobilization (4 regional offices)
- Local, Regional, and Statewide Partnerships
- Over 31 Telemedicine Linkages
- Community and Health Professional Education
- Clinical Trials Infrastructure, Awareness and Promotion
- Faculty Outreach projects
- Health Behavior Needs Assessment Survey
- Latino Health Initiative Partnership – Montgomery County
- Designated national “Best Practice Award” from Secretary US Department of Health and Human Services: Model for Increasing Availability of Community-Based Clinical Trials on the Rural Eastern Shore
- CME/CEs for local physicians and nurses on cancer, clinical guidelines, tobacco-related diseases, including recruitment to clinical trials

UMSHN Community and Telemedicine/Videoconference Linkages Unique Infrastructure



**NCMHD/NIH P60 Export Center at the
University of Maryland:
A Comprehensive Center for Health
Disparities Research, Training
and Outreach**

**University of Maryland School of Medicine
and
University of Maryland Eastern Shore**

Mission

- To reduce and eliminate health disparities in Maryland's urban and rural underserved communities through an intensive and integrated program of multidisciplinary research* and community outreach and training, which fosters *health disparity discovery, intervention and translation*.

**preclinical, clinical, population sciences, behavioral, palliative care*

Geographic and Population Focus

- Geographic Focus: State of Maryland

- Target Populations:

- Urban and rural underserved communities
- Racial/ethnic minorities including African Americans, Native Americans, Latinos and Asians
- Low Income

P60 Cancer Core Research Interactions

- Viral Carcinogenesis
 - HPV oncogenicity in adolescents
 - HBV/HCV and HCC etiology
 - HIV and tumor biology in adolescents
- Prostate and Breast cancers
 - Disparities in prognostic factors
 - Survivorship research
 - Abnormal screening follow up
 - Gene expression racial variation
- Clinical Trial Recruitment and Retention
 - Research on strategies to increase recruitment and retention of diverse populations in clinical studies
 - U.S. Department of Health and Human Services “National Best Practice” Award

Selected Recent Cancer-Related Publications

1. Baquet CR, Commiskey P, Mack K, Meltzer S, Mishra SI: "Esophageal cancer epidemiology in blacks and whites: racial and gender disparities in incidence, mortality, survival rates and histology. Journal of the National Medical Association, 2005; 97(11): 1471-1478.
2. Baquet CR, Mishra SI, Commiskey P, Khanna N. "Clinical trials: a strategy for improving health and reducing health disparities". Maryland Family Doctor, Winter 2006: 9-12.
3. Baquet CR, Mishra SI, Commiskey P, Ellison G. "Regional and racial differences in cancer screening practices in Maryland" Journal of the Association for Academic Minority Physicians, 2005; 16: 19-27.
4. Baquet CR, Commiskey P, Mullins CD, Mishra SI. "Recruitment and Participation in Clinical Trials: Socio-demographic, rural, urban and healthcare access predictors. Cancer Detection and Prevention. 2006; 30(1) 24-33.
5. Mullins CD, Blatt L, Gbarayor CM, Yang H-W-K, Baquet C. "Health Disparities: A Barrier to High Quality Care". American Journal Health - Syst Pharm 2005; 62 Sept 15:1873-1882.

Community Networks and Partnerships

- Baltimore Times Community Foundation
- University of Maryland Statewide Health Network (UMSHN) sites
- Federally Qualified Health Centers (FQHCs)
- Montgomery County Latino Health Initiative
- UM-School Partners
- Sisters Surviving
- Ministerial Alliances
- Native American Workgroup
- Montgomery County Health Department
- Baltimore County Health Department
- Anne Arundel County Health Department
- Maryland Center at Bowie State University
- Southern Maryland

Maryland Regional Community Network Program (CNP)

Community Network Program Mission

- To reduce and eliminate cancer disparities for Maryland's urban and rural underserved communities through:
 - Community-based participatory research
 - Enhanced uptake of evidence-based, culturally appropriate beneficial interventions for community, patients, survivors, and caregivers
 - Training of new cancer researchers
 - Science guided policy development
 - Sustainability

Target Populations

- Statewide Focus
- African Americans
- Latinos
- Native Americans
- Low-income Whites
- Rural
- Urban



Focus Areas

■ Cancers

- Breast
- Cervical
- Colorectal
- Liver
- Oral
- Prostate

■ Risk Behaviors

- Tobacco Cessation
- Clinical Trials
Knowledge and
Behaviors
- Diet and energy
balance

Regional Community Partners

■ Baltimore Metro Region

- Times Community Services Inc.

■ Southern Maryland Region

- C-Datcher & Associates, LLC

■ Eastern Shore Region

- Eastern Shore Oncology, PC

■ Baltimore Medical Systems, Inc.

- FQHC

■ Maryland Capital Region

- The Maryland Center at Bowie State University

■ Northwest Maryland Region

- Western Maryland AHEC

■ Statewide Native American

- Piscataway Conoy Confederacy & Subtribes, Inc.

Maryland Community Clinical Trial Program

Ministers and churches, health professionals

Eastern Shore Oncology-UMSOM

- Rural Community Cancer Clinical Trials Education and Availability Focus
- Multi-Pronged Approach
 - Community education and awareness
 - Physician and other health professional continuing education
 - Trial infrastructure development; clinical nurse educator and nurse clinical trial data manager
- Outcomes:
 - In five years: 16-fold increase in number open cancer protocols
 - 40-fold increase patient accrual to trials
 - 25% rural African American cancer patients
 - Favorable external rigorous audits by: CTSU, ECOG, other CGs
- Maryland surveys and qualitative research to identify barriers to clinical trials:
 - 80.0% of Blacks and 50.9% of Whites reported not knowing what a clinical trial is.
 - Over 95% of all respondents reported their physician never discussed clinical research/trials.
- “National Best Practice Award” from DHHS Secretary and Committee on Science and Policy HHS “A Model for Increasing Availability of Community-Based Cancer Trials in Rural Eastern Shore, MD September 2004
ASHBESTPRACTICES@LIST.NIH.GOV

Supported by: MSPN/CNP NCI ; MD CRF; Susan G. Komen Foundation Maryland; NIH NCHMD P 606

Survivorship Research

Selected Examples

African American Breast Cancer Survivors: Sisters Surviving

- Qualitative and quantitative research design (focus group and telephone interviews)
- 25 breast cancer survivors between 28 and 82 years of age
- Themes:
 - God's punishment
 - Guilt
 - Fear
 - Family desertion
 - Cultural incompetence of physicians (minority and non-minority) and their office staff
 - Perceptions by patients that provider judged them because of their race and felt they were on public assistance.
 - Lack of pain control ("provider thought I was a junkie")
 - Lack of access to same skin color breast prostheses
 - Desire for correct and literacy appropriate information on cancer

Rural African American Cancer Survivors: Qualitative Research

- Central themes and concerns related to:
 - Transportation to therapy and lack of literacy appropriate survivorship support and information
 - Inadequate pain management and perception that providers assumed they were “drug addicts” when seeking pain control
 - Lack of nutrition information
 - Perception that physician dismissed the patient’s need for spiritual counseling

First Degree Relatives of Breast Cancer Survivors Study

- Qualitative research (focus groups) to assess the risk perceptions, screening behaviors and barriers among first degree relatives of breast cancer survivors.
- The project conducted three focus group discussions:
 - 18 African-American participants (17 women, 1 man) ranging from 36-92 years of age
 - The majority of participants resided in the Baltimore City area.

Focus Group: First Degree Relatives of Breast Cancer Survivors

- The majority of the participants believed they were at risk for developing breast cancer due to family history and/or prior abnormal breast examinations.
- Participants identified the following as risk factors for the disease: smoking, diet, lack of physical exercise, environment and birth control pills.
- A few participants associated excessive thoughts about breast cancer and a negative attitude could increase a person's risk of developing the disease.
- Most participants indicated that they received mammograms on a yearly basis often along with their pap test.
- Participants reported beginning their mammograms in their late 30s to early 40s.

Health Policy and Disparities Research

The Role of Policy and Health Disparities: The Link

Health Disparities Research can:

- Document/describe the existence of health disparities
- Contribute to the understanding of the etiology of health disparities
- Assist in defining nature/extent of health disparities
- Inform and guide policy maker's agenda
- Influence the development of science-guided policy/interventions to reduce or eliminate health disparities
- Evaluate policies with regard to whether desired outcomes are achieved
- Foster sustainability and leveraging

A Specific Example of the Health Disparities Research/Policy Connection: Mandated Benefits Legislation

- **Mandated Benefits** are required health insurance benefits or services that health plans must include (developed in response to cost cutting initiatives by HMOs etc.).
- Maryland has 40 mandates.
- Mandates do not apply to small group market, Medicaid or the self insured (about 75% of the population under 65 years are not covered by mandates; mandates influence what is covered and the extent of coverage in other markets).
- Mandates cover a number of cancer related services.

Mandates for prevention, screening and treatment in Insurance Article

- 15-804 Coverage for off label use of drugs
- 15-809 Hospice Care
- 15-814 Mammography coverage
- 15-815 Reconstructive Breast Surgery coverage
- 15-825 Prostate Cancer screening coverage
- 15-827 Clinical trials coverage
- 15-832 Length of stay mastectomies and prostate surgery
- 15-834 Prosthesis after mastectomy
- 15-836 Wigs after chemotherapy
- 150837 Colorectal cancer screening

Future Research

- Well-designed studies intersecting cancer disparities and survivorship, including policy research
- Examine and enhance cultural competence of health professionals to address survivorship issues
- Alternative (integrative and complementary medicine) therapies to enhance quality of life among survivors
- Patterns of care among survivors
- Disparity issues related to appropriate pain control; energy balance; acupuncture; stress management